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**OCCURRENCE OF AUTISM SPECTRUM DISORDER IN THE
HEARING-IMPAIRED POPULATION:
HOW TO ACHIEVE EARLIER DIAGNOSIS**

by

Laura Elizabeth Saia

**An independent study
submitted in partial fulfillment of the
requirements for the degree of:**

Master of Science in Deaf Education

**Washington University School of Medicine
Program in Audiology and Communication Sciences**

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**Approved by:
Christine Clark, M.A, CED, Independent Study Advisor**

Introduction

Autism Spectrum Disorder (ASD) is a title that encompasses a broad range of disorders and syndromes that all present with similar clusters of symptoms. Some conditions included under this title are: Rett Syndrome, Childhood Disintegrative Disorder, Asperger Syndrome, Pervasive Developmental Disorder, and Autism. Present in all of these are abnormalities in three areas: deficits in social interaction, deficits in verbal and nonverbal communication, and an increase in repetitive behaviors or interests. There are often atypical responses to various forms of sensory stimuli as well. Regardless of these commonalities, the presentation of symptoms is highly variable, even within the same syndrome, and can be anywhere from mild to severe.

Diagnosis of ASD usually begins with completion of a rating form or parent interview. Some commonly used tools include: Checklist for Autism in Toddlers (CHAT), Pervasive Developmental Disorders Screening Test-II (PDDST-II), Autism Diagnostic Interview—Revised (ADI-R), Childhood Autism Rating Scale (CARS), and the Autism Behavior Checklist (ABC). (Blackwell and Niederhauser, 2003) Some questions on the PDDST-II include:

- Does your toddler sometimes stare or tune out, making it hard to get his attention?
- Does your baby ignore toys most of the time, or play almost all the time with one or two things?
- Does your toddler ever seem bored or uninterested in conversations around him?
- Have you worried that your child doesn't seem too interested in other children?
- Does your child ever seem to forget old words when he learns new words?
- Does your baby stare at his fingers while turning them, or use his fingers to stare at patterns of light?

- Has anyone expressed concern that your baby might have a hearing loss?
- Does your baby's mood sometimes change suddenly for no real reason?
- Does your baby seem uninterested in learning to talk?
- Does your child walk on his toes, especially when he is excited?
- Does your child try to get away with using as few words as possible?
- Have you or anyone else ever felt that your child's tone of voice is too flat, sing-songy, or high-pitched?

The questions on the PDDST-II are all answered by parents with "yes" or "no," then the professional completing the test will score those responses. The CARS addresses the same areas, but in a different fashion. The CARS has fifteen sections, each relating to a different area of functioning. These include relating to people; emotional response; imitation; body use; object use; listening response; adaptation to change; taste, smell, and touch response and use; visual response; fear or nervousness; verbal communication; activity level; nonverbal communication; level and consistency of intellectual response; and general impressions. A rater must be trained in the use of the CARS (Blackwell and Niederhauser, 2003) and completes it through observation of the child in question, rating the child on a scale of one to four in each area. A higher score indicates more severe autism.

Incidence of ASD is not well-defined, but is theorized to be between 2 and 6 children per 1,000 children. (NIMH, 2004). While this may seem small, the current figures represent a tenfold increase in the past decade. (UM News Service, 2004) There has not been a satisfactory explanation for this increase, but it has augmented the amount of research about and interest in children with ASD.

Children with hearing impairment seem to have an increased chance of also having ASD. As reported in Donaldson et al. (2004), various studies have proposed incidence rates for ASD in the hearing impaired population, ranging from their own finding of 1.7% to as high as 13%. Clearly, all of these rates greatly exceed the figure of 2 to 6 per 1,000 (0.2-0.6%). In addition, children with hearing impairment have experienced a significant delay in the diagnosis of ASD due to the similar impairments in communication and social skills typically displayed in hearing-impaired children. Roper et al. (2003) found that when comparing deaf autistic and hearing autistic children, hearing impaired children were diagnosed with autism significantly later than their hearing peers (mean age for deaf group: 15 years; mean age for hearing group: 7 years, 5 months.) However, parents noticed abnormal symptoms around the same time for both groups. It seems reasonable to assume that once the hearing impairment was diagnosed, parents were persuaded that any residual abnormal behaviors or issues were related only to the hearing impairment and not to anything else. Only following a lack of anticipated progress were other possibilities explored.

In addition, considering the type of questions included on commonly used diagnostic tools such as the CARS and the PDDST-II, it is not surprising that professionals would be wary of making the additional diagnosis. Some questions from the PDDST-II, such as “Does your child seem bored or uninterested in conversations around him?” or “Does your child try to get away with using as few words as possible?” are questions that could commonly be answered “yes” by a parent of a hearing-impaired child. “Yes” is also the answer expected for a child with autism. With many categories on the CARS, a hearing-impaired child may be rated higher (worse) on an area due to the hearing loss. One salient example is the section on listening response. Though a typical child with hearing loss would not rate as high as a four, the child

may often net a score of two: “There may be some lack of response, or mild overreaction to certain sounds. Responses to sounds may be delayed, and sounds may need repetition to catch the child’s attention. The child may be distracted by extraneous sounds.” Similar scoring dilemmas may occur in the sections on adaptation to change (a child with hearing impairment may act adversely to change if he or she is surprised by the change or does not understand it), fear or nervousness (a child may be more nervous if he or she cannot follow what is going on), and verbal communication (due to the language and speech delays associated with hearing impairment).

Since Roper et al. (2003) conducted their study on teenaged students, it is possible that with the advent of newborn hearing screening, some of this confusion over etiology of symptoms may be decreased. If a child is diagnosed with a hearing impairment at only a few months of age and the symptoms of ASD appear around 18 months of age (NIMH, 2004), there is a possibility that the level of hearing impairment (and any resulting issues) will be already well-known enough that the additional symptoms of ASD would be more easily recognized and separated from the extant condition.

Complicating the situation are certain impairments that are evident in both the hearing impaired and ASD-affected populations. Language and communication deficits are often the most noticeable and impairing for these children, but early intervention programs for both populations target these skills in particular. Another area of impairment for both populations is development of theory of mind (ToM). ToM is defined as “the ability to recognise people’s inner mental states... while using these inferred psychological attributes to understand and predict behaviour.” (Peterson, 2004) Typically-developing children usually fail tests for theory of mind at age three, but mainly pass them by age five. Children with autism and children with

deafness are found to have significant delays in their acquisition of ToM. However, their failure or success in the tests seems to have a direct connection to their language levels or “verbal maturity,” suggesting that improvements in their communication and language skills will improve their performance on ToM measures. (Peterson, 2004) Success in utilizing ToM is important for proper social awareness and appropriate interaction with others.

Due to the pervasive character of ASD and the progression of symptoms, early intervention is key for future success. According to NIMH (2004), “...early intervention has a dramatic impact on reducing symptoms and increasing a child’s ability to grow and learn new skills.” Structured, communication- and social skills-intensive programs have been found to be the most effective programs for most children with ASD. As reported by UM News Service (2004), a researcher (Catherine Lord) has found that with diagnosis and intervention using appropriate therapies close to age two, there can be little to no evidence of ASD by age nine. She has also found that very few children who have appropriate intervention have persistent difficulties in communication. Therefore, it is imperative to find reliable ways to diagnose ASD in children as early as possible to give them the best chance of success. For children with hearing impairment, it is even more important to make the distinction between hearing impairment and hearing impairment plus ASD in order to provide appropriate intervention as early as possible.

Purpose

The current study addressed the need for earlier diagnosis of ASD in children with hearing impairment. The current delay in diagnosis may be a significant obstacle to the long-term success of these children. The researcher’s goal was to develop a set of guidelines for

earlier diagnosis based on indicators specific to hearing impaired children with autism versus hearing children with autism.

Method

The researcher developed a survey to determine the incidence of children with a dual diagnosis of hearing impairment and autism in schools for the deaf. (Appendix A) Demographic characteristics of the school were addressed, such as number of students, whether therapy was home-based or center-based, and what method of communication was typically used (oral, sign, total communication (TC), or augmentative communication). Next, the professional completing the survey was asked to give details about any students in their program who had (a) a diagnosis of ASD in addition to hearing impairment and (b) suspected ASD in addition to hearing impairment. These details included: age at diagnosis of hearing impairment, age at diagnosis of ASD, symptoms leading to ASD diagnosis, device(s) used, method(s) of communication used, and any other relevant case history. Finally, there were several questions addressing the professional's personal views on the issue of ASD in the hearing impaired population, such as if he or she felt the current system of diagnosis was sufficient and how he or she would like to see the system changed.

This survey, along with a cover letter (Appendix B) was sent to twenty schools for the deaf. Oral schools were found on Oral Deaf Education's website, <http://www.oraldeafed.org>. Schools from across the country were selected. Sign/TC programs were found by searching online for state schools/programs in the same states as the oral programs.

Results

Ten surveys of the twenty were returned. All returned surveys were from oral programs. Of the ten returned, five reported students with ASD symptoms, and two of these have only had

a child with suspected ASD. As the children reported on in this study were much younger than those in the Roper et al. (2003) study, the large delay in diagnosis was not as evident; children in this survey were diagnosed with autism between age two and age four. These children had varying abilities to utilize oral language as their primary mode of communication; two were labeled as only oral, while the others were labeled as oral in addition to using some other gestural form of communication. In the case of one student, cued speech had been recommended in order to increase oral fluency.

With regard to symptomology of ASD in children with hearing impairment, there were not any discernable patterns in the reported indicators. Indicators included: self-abuse, self-stimulation (“stimming”), sensitivity to sensory input, tactile defensiveness, poor eye contact, inability to stay on task, disinterest or disengagement in group activities, echolalia, and slow processing of input. Notably, no communication or language skills were addressed in the reported symptoms, though some social skills limitations were mentioned.

Of the five professionals that commented on the importance of the issue of this dual diagnosis, all felt that early diagnosis and intervention were key to success. Several expressed concerns about the expertise of the people making observations and referrals; with the increased discussion of ASD in the popular media, people may make assumptions without following systematic observation procedures for accurate diagnosis. One professional even mentioned the potential utility of a specialized curriculum for these dually-diagnosed children. This same professional also indicated that she felt the “structured environment and language bombardment given hearing impaired students offers helpful stimulation to children with ASD as well.” Another said, “I’m pleased that someone is looking into this—I feel that we’re all going to be

seeing more [hearing impaired], Autistic [children] who are implanted—this is a big issue in the field.”

Discussion

The present study was unable to compose a list of symptoms specific to children with hearing impairment. This is not surprising as the presentation of ASD is so variable; it is difficult to form a reliable list of symptoms even if the child does not have any other impairments. However, the notable lack of report of language and communication skills when indicating symptoms of ASD as evidenced by this study may give a clue to the difficulty of accurate diagnosis of ASD in this population. As discussed above, verbal and nonverbal communication skills represent a third of the criteria for diagnosing ASD, while social skills represent another third. Children with hearing impairment often display impairments in these two areas, particularly at young ages when intervention has just begun. When other abnormal symptoms are present, they may be ignored or deemphasized due to the language and social deficits potentially being explained by the hearing impairment; ASD could not be diagnosed with only a third of relevant symptoms present. It will be important for future research to continue to examine the indicators of ASD in the hearing impaired population in order to prevent the dismissal of potentially important symptoms, which could delay appropriate intervention and reduce the possibility of future success.

Regardless of the ability to properly diagnose ASD in the hearing impaired population, it is fortunate that the early intervention programs for hearing impaired children have a strong focus on language and communication development. This focus will benefit children with ASD, such that despite a lack of diagnosis, proper intervention may already be occurring. However, it is important to always be cognizant of a child's progress and if it is occurring at an acceptable

rate. If not, it is imperative to adjust the educational intervention and/or seek out additional resources. It is key to have appropriate intervention so that a child may develop his or her communication and social skills to their full potential, providing him or her with the best opportunity for success.

In the future, more research needs to be completed in this area. A similar survey sent to public schools or schools for children with autism may yield insightful results as schools for the deaf may not always accept multiply-involved children. In addition, schools specifically serving children with autism may be valuable reporters because as professionals who are confronted with ASD symptomology on a daily basis, they may be better able to isolate symptoms associated with a specific population. Another area of research that should be addressed is the issue of newborn hearing screening and its effect on appropriate diagnosis of syndromes present in addition to hearing impairment. Though it seems that earlier identification of hearing impairment should have a positive effect on the ability to make further diagnoses, research is necessary to prove a relationship.

ASD is increasing in the general population as well as within the hearing-impaired population. The resultant impairments of ASD, especially in language and social skills, can have a huge impact on children with hearing impairment who already face challenges in these areas. Previous studies as well as professional opinions indicate that early intervention and intense programs that focus on language, communication, and social skills offer the best opportunity for success in the lives of children with ASD, whether hearing or hearing-impaired.

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Appendix A

Survey

Please complete this survey as completely as possible. Any and all information is greatly appreciated!

****For the purposes of this survey, Autism Spectrum Disorders** will include any disorders on the Autism spectrum, including Autism, Asperger's Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder (PDD).

1. (OPTIONAL) What is the name of your program? _____

2. What is your position in this program? _____

3. How many children are currently enrolled in your program?

a. Center-based _____

b. Home-based _____

4. What ages of children does your program serve? _____

5. How would you define the population you serve? _____

6. What is the preferred mode of communication in your program? (circle one or more)

Oral

Total Communication

Sign

Augmentative Communication

7. How many students currently enrolled in your program have a dual diagnosis of hearing impairment and an autism spectrum disorder? _____
8. For those students, please complete the following chart, noting their current age, their age at diagnosis of hearing impairment, their degree of loss and device(s) worn, their primary mode of communication, their age at diagnosis of an autism spectrum disorder, whatever indicators alerted the parents/caregivers/teacher/other professional that the child had an autism spectrum disorder, and any comments about the specific case (other factors, etc.).

Current Age	Age at diagnosis (H)	Degree of loss/device(s) worn	Primary Communication Mode	Age at diagnosis (A)	Indicators of ASD	Comments

9. Are there any children in your program currently diagnosed with a hearing impairment and a parent/caregiver/teacher/other professional has indicated concern that the child might have an autism spectrum disorder? _____ Yes _____ No

If yes, what behaviors (or other indicators) have influenced this suspicion?

10. Do you feel the system for diagnosing Autism Spectrum Disorders could be improved, especially in the case of hearing impaired children? If so, how would you improve it?

11. If you have any other comments or questions, please feel free to share them in the space below.

Appendix B

Cover Letter

Dear Deaf Educator,

My name is Laura Saia and I am a student at Washington University School of Medicine working on my Master's in Education of the Hearing Impaired. For my independent study, I am interested in researching the incidence of Autism Spectrum Disorders (ASD) in children with a hearing impairment and how the hearing impairment affects the timeliness of an ASD diagnosis.

It is clear that both disabilities have a profound effect on language and speech development. When ASD goes undiagnosed, the particular educational needs of a child with autism may be different than what is available in a typical educational setting, whether it is a public school or a deaf education setting. In that case, the child's development may be delayed even further.

I have included a short survey and I would appreciate any input you may have on this subject. Please return the survey in the enclosed envelope as soon as possible, no later than February 1, 2005. If you have any questions, or if you would like a copy of the results of my study, you can contact me at (314) 645-2224 or through email at laurasaia@alum.wustl.edu. Thank you so much for your time!

Sincerely,

Laura Saia
WUSM/CID

****This letter was sent on program letterhead.**